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Original Article

Opportunities for cystic fibrosis care teams to support treatment adherence

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Abstract

Background: The purpose of this study was to identify the extent to which pediatric and adult cystic fibrosis (CF) care teams implement best practices in adherence assessment and counseling.
Methods: All US CF Foundation accredited programs were invited to participate in a web-based survey; 80% (92/115) of pediatric and 40% (38/95) of adult centers participated. Health care providers reported on current approaches and barriers to implementing adherence promotion practices.
Results: 64% discussed adherence at every clinic visit while only 8% used an objective assessment of adherence. Most centers reported frequent use of strategies to increase knowledge; behavioral and support strategies were used less regularly. Several barriers to adherence promotion were reported.
Conclusions: Many opportunities exist for care teams to improve consistency in adherence practices and integrate a greater repertoire of effective counseling strategies into clinic visits. Adherence promotion practices should be considered for quality improvement (QI) projects.
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Keywords: Adherence; Counseling; Education; Provider; Barriers

1. Introduction

The lifespan for people with cystic fibrosis (CF) has markedly improved and is attributable to the development of new treatments. Unfortunately, these advances have resulted in a complex and time-consuming home program of self-care making perfect adherence an unreasonable expectation [1]. Indeed, objective medication adherence estimates range from 48 to 63%, with nonadherence prevalent across the lifespan and associated with poor health outcomes [2,3]. Moreover, CF physicians identify patient nonadherence as a common barrier to providing guideline-based care [4]. Therefore, supporting adherence is an important role for healthcare providers to ensure people with CF fully benefit from available therapies [5].

Healthcare provider–patient relationship factors such as communication, support, trust, and inclusion in decision-making are associated with better adherence in many diseases [6–8]. Among adults with CF, a commonly identified facilitator of adherence is attending clinic visits in part due to the support they receive from their care team [9]. Despite the importance of provider–patient relationships in improving adherence, many healthcare providers feel uncomfortable or ill-equipped to provide behavioral counseling [10]. Healthcare providers also cite practical barriers to providing adherence counseling such

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as limited time, inadequate reimbursement, and limited resources [11].

Extrapolating from communication research [12], one can posit that adherence will be maximized when there is consistency in how providers handle nonadherence, ongoing assessment of adherence, and the provision of quality, evidence-based counseling. *Consistency* ensures the patient receives a clear and congruent message about the importance of adherence from all care team members. Ongoing *Assessment* includes the systematic use of objective measures to reliably identify nonadherence. Quality *Counseling* employs empirically validated educational, behavioral, and support strategies to promote improved adherence. Understanding current practices is critical to developing new, effective, and sustainable clinic-based programs to support adherence promotion [13]. Clinics are unlikely to adopt strategies, no matter how efficacious, if the strategies are not perceived as feasible to implement. Therefore, the goal of this study was to survey CF care centers for perceptions of adherence practices in the areas of consistency, assessment approaches, and counseling strategies used. We also aimed to elicit perceived barriers to adherence promotion in order to identify areas of strength and opportunities for intervention. We examined these variables overall, and by pediatric and adult centers, to determine if pediatric and adult providers use different strategies.

2 . Methods

2.1 . Procedures

All United States CF Foundation accredited pediatric and adult care center directors and nurse coordinators were emailed an invitation from the CF Foundation Director of Patient Resources and Vice President for Clinical Affairs asking the center to participate in a web-based survey on adherence practices. Each center was asked to submit one survey with the recommendation that it be completed by the nurse coordinator using feedback from the center director and care team. Five email reminders were sent and the survey was available for one month. The Johns Hopkins University Institutional Review Board approved all study procedures. Portions of these data were presented at the North American Cystic Fibrosis Conference Orlando FL October 23–25, 2008 [14].

2.2 . Survey

The survey included the respondent's demographic characteristics and estimates of the average total time allocated for a regular quarterly clinic visit and the amount of time spent counseling about adherence during these visits. Proportion of time allocated to adherence was calculated by creating a ratio with the number of minutes spent on adherence counseling as the numerator and the total number of minutes for a regular quarterly visit as the denominator. Items that assessed consistency of adherence discussions, assessment approach, counseling practices, and barriers were adapted from Golin et al. [11]. To keep the survey brief and because practice may vary by different treatment expectations, all survey questions were specific to medication adherence.

2.2.1 . Consistency

Respondents were asked to select one of four statements that best matched their center's practice for discussing adherence ("Medication adherence is discussed with the patient/parent only when there is a concern about declining health", "If a patient's health is fine, medication adherence is formally discussed only at the annual visit", "Medication adherence is discussed with every patient/parent at every clinic visit regardless of his/her health status", or "There is no consistent practice for discussing adherence with a patient/parent"). Respondents also answered a single item ("Our care center has a consistent approach or philosophy for intervening when we identify a patient/parent who is nonadherent") on a 5-point Likert scale, ranging from strongly agree to strongly disagree.

2.2.2 . Assessment approach

Respondents indicated how often ("never", "rarely", "sometimes", "most of the time", or "all of the time") they used various assessment strategies listed in Fig. 1 to identify medication nonadherence.

2.2.3 . Counseling practices

Respondents rated how often they used common counseling strategies to promote patient medication adherence on a 4-point Likert scale ("never", "sometimes", "most of the time", or "all of the time"; see Table 1 for items).

2.2.4 . Barriers

Previously identified barriers to adherence promotion were queried on a 5-point Likert scale, ranging from 4 = strongly agree to 0 = strongly disagree (see Table 2 for items). Respondents were also asked whether they would be interested in learning an adherence program that took 5 min or 15 min to implement to assess the impact of clinic-based time constraints on adherence promotion.

2.3 . Statistical analyses

When multiple surveys were received from a single center, one survey was selected using the following prioritization: nurse coordinator, center director, physician, and other team member. Descriptive frequencies of provider characteristics were generated using means and proportions as appropriate. Statistical comparisons between groups were made using 2-tailed t-tests and chi-square tests as appropriate. STATA 13.1 (StataCorp LP, College Station, TX) was used for all statistical analyses. P-values < 0.05 were considered statistically significant.

3. Results

One hundred fifteen pediatric and ninety-five adult CF care centers were invited to participate; at least one team member from 80% (n = 92) of pediatric care centers and 40% (n = 38) of adult care centers submitted a survey. Respondents had varying care team roles, including nurse coordinators (59%), physicians (19%), and center directors (11%). Most participants were female (62%) and had worked in CF for more than 5 years

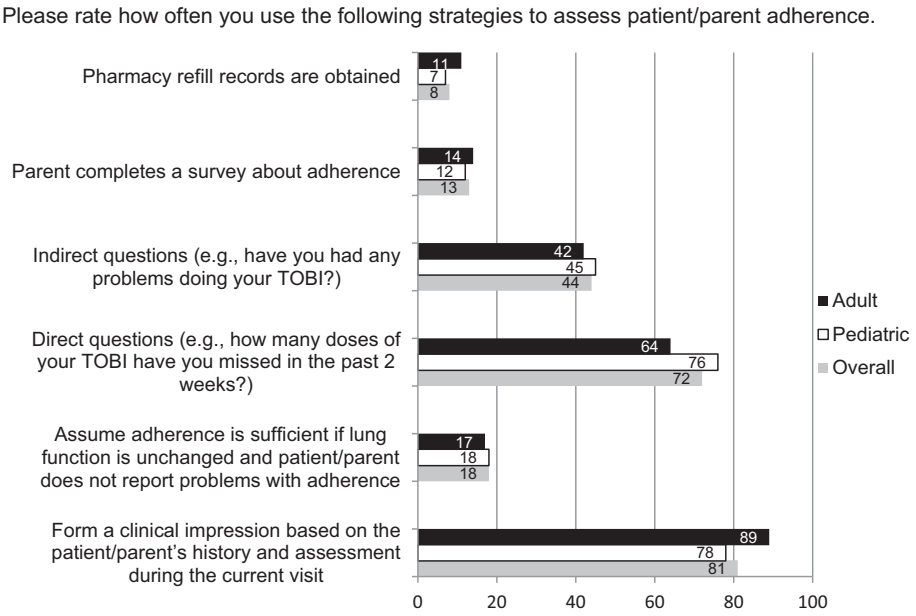

Fig. 1. Percent of CF care centers endorsing each assessment strategy.

(83%). Centers reported a median length of a regular clinic visit to be 60 (IQR 30, 60) minutes and they dedicated a median of 17% (IQR 13%, 33%) of visit time to addressing adherence with no differences between pediatric and adult centers. Almost all healthcare providers agreed or strongly agreed that nonadherence is a major contributor to CF morbidity and mortality (91% and 86% respectively) again with no differences between pediatric and adult centers.

3.1. Consistency

Among respondents, 65% said adherence was discussed at every visit, while 23% reported no standard practice for discussing adherence and the remainder (12%) discussed adherence only with a decline in the patient's health or at the annual visit. Only 48% of the participants agreed or strongly agreed that their center employs a consistent approach or philosophy for intervening when a patient is nonadherent, while 28% disagreed or strongly disagreed. There were no differences between pediatric and adult centers.

3.2. Assessment approach

Centers rarely used an objective assessment of adherence (e.g., pharmacy refill data; Fig. 1), with the vast majority relying on clinical impression or direct questions. Several respondents indicated that they assumed adherence was fine if pulmonary

Table 1
Percent of CF centers reporting performance of adherence counseling activities most or all the time.

	Overall N = 125 N (%)	Adult n = 36 N (%)	Pediatric n = 89 N (%)	p
Educational strategies				
Ask if patient/parent has questions or concerns about their treatment	109 (88)	28 (78)	81 (92)	0.027
Review the dosing schedule for each prescribed medicine	108 (86)	29 (81)	79 (89)	0.225
Discuss consequences of nonadherence	98 (78)	28 (78)	70 (79)	0.914
Provide written dosing instructions	86 (69)	19 (53)	67 (75)	0.014
Ask the patient/parent to repeat or rehearse dosing instructions	54 (44)	10 (28)	44 (51)	0.020
Explain what to do if a dose is missed	42 (34)	11 (31)	31 (35)	0.618
Behavioral strategies				
Include the patient/parent in decisions about changes to the regimen	109 (87)	31 (86)	78 (88)	0.817
Ask about barriers that make it hard to follow treatment regimen	91 (73)	23 (64)	68 (76)	0.154
Help patient/parent plan dosing times to fit his/her daily routine	68 (55)	17 (47)	51 (58)	0.276
Suggest strategies to remember when to take medication	64 (51)	17 (47)	47 (53)	0.571
Encourage the use of reminder systems (e.g., diary, pill box)	52 (42)	12 (34)	40 (45)	0.279
Social support and encouragement				
Ask a nonadherent patient/parent to return to clinic sooner	99 (80)	27 (75)	72 (82)	0.390
Ask about availability of social support (e.g., family, friends) to encourage adherence	72 (58)	20 (57)	52 (58)	0.896
Telephone or email a patient/parent to follow up on medication use or side effects	25 (20)	12 (33)	13 (15)	0.018

Table 2
Mean (SD) and percent of respondents who agree or strongly agree (A/SA) with each barrier to adherence counseling.

Barrier to adherence counseling	Overall N = 121		Adult N = 35		Pediatric N = 86	
	M (SD)	N (%) A/SA	M (SD)	n (%) A/SA	M (SD)	n (%) A/SA
Adherence counseling is a good use of my time	3.1 (0.6)	104 (87)	3.1 (0.6)	31 (89)	3.1 (0.6)	73 (86)
I am adequately trained to provide adherence counseling	2.8 (0.9)	84 (69)	2.9 (0.9)	26 (74)	2.8 (0.9)	58 (67)
I have the skills necessary to provide quality adherence counseling	2.8 (0.8)	81 (68)	2.9 (0.8)	26 (74)	2.7 (0.8)	55 (65)
What the CF health care team says to a patient/parent significantly affects adherence	2.7 (0.7)	79 (65)	2.7 (0.9)	22 (63)	2.7 (0.7)	57 (66)
Adherence counseling done during clinic time is effective in increasing patient/parent adherence	2.7 (0.7)	72 (60)	2.7 (0.7)	22 (63)	2.7 (0.7)	50 (58)
There is adequate time during a clinic visit to provide adherence counseling	2.5 (1.0)	77 (64)	2.8 (0.9)	25 (71)	2.4 (1.1)	52 (60)
Our team has sufficient access to experts who can counsel patients/parents about adherence (e.g., psychologists, psychiatrists, social workers, pharmacists)	2.3 (1.2)	61 (50)	2.3 (1.2)	18 (51)	2.3 (1.1)	43 (50)
There is enough clinic/office space to provide adherence counseling	2.0 (1.2)	53 (44)	2.5 (1.1)	23 (66)	1.8 (1.2)[a]	30 (35[a])
Reimbursement is adequate for providing adherence counseling	1.3 (1.0)	15 (12)	1.7 (0.9)	6 (17)	1.1 (1.0)[a]	9 (10)

[a] $p < 0.01$.

function results were unchanged. There were no differences between pediatric and adult centers.

3.3 . Counseling strategies

3.3.1 . Educational

Most strategies to increase patient/parent knowledge were highly endorsed (Table 1). Fewer centers regularly used more time consuming yet effective educational strategies such as providing written dosing instructions (69%) and asking a patient or parent to repeat dosing instructions (44%); moreover, the adult group was significantly less likely to report use of these two strategies compared to the pediatric group ($p < .05$). Only a third of centers provided guidance on what patients should do if they realize they missed a treatment dose.

3.3.2. Behavioral

There was high endorsement for including patients and families in decisions about regimen changes and asking about treatment barriers. It is notable, however, that approximately half of centers or fewer regularly used effective behavioral strategies to support adherence including helping patients plan dosing time to fit their daily routine (55%), suggesting strategies to remember to take medicine (51%), and encouraging the use of reminder systems (42%). No differences were found between pediatric and adult centers in the use of behavioral strategies.

3.3.3. Support

Respondents regularly requested that patients return to clinic sooner (80%) when adherence concerns existed. However, little more than half of respondents asked about available social support and few respondents called or emailed a patient after a visit to follow up on adherence problems. Interestingly, adult centers were more likely to telephone or email patients after clinic visits than those from pediatric centers ($p < .05$).

3.4. Barriers to providing adherence counseling

Approximately two-thirds of respondents agreed that they had the necessary training and skills to provide counseling although 40% were not convinced that their counseling was efficacious (Table 2). Similarly two-thirds of the respondent agreed that there was enough time during clinic visits to provide adherence counseling while fewer felt that sufficient clinic space was available to them and almost none agreed that they were adequately reimbursed for adherence promotion. On average, respondents from pediatric centers were less likely to agree that they had adequate space and reimbursement for adherence counseling than adult centers ($p < 0.01$). Only half the centers agreed that they had access to professionals with expertise in adherence counseling. Finally, interest in learning an adherence intervention dropped considerably from 64% being extremely interested to 31% ($p < .0001$) when the hypothetical time commitment for counseling increased from 5 to 15 min per patient. Table 3 provides responses from a comment section that illustrates these barriers. No new barriers were identified from evaluation of responses to the open-ended question.

4 . Discussion

In other chronic illnesses, the patient–provider relationship has been shown to be associated with improved adherence and there are several behaviors that a healthcare provider can use to promote adherence [7,15,16]. In CF, adults with CF indicate that clinic visits support their attempts to adhere to their regimen [9]. The findings from this investigation of US CF care centers' medication adherence promotion practices suggests that, although almost 20% of the visit is perceived to be dedicated to adherence promotion, there is high variability in adherence practices across US CF Care Centers and many potential opportunities for intervening are missed. An encouraging finding was that there was near universal agreement among respondents that regimen adherence is essential for increasing lifespan and decreasing morbidity among patients with CF. Remarkably, there were few differences between pediatric and adult centers.

The first step in addressing nonadherence is identifying it; however, 35% of centers do not assess medication adherence at every visit. Furthermore, the use of reliable and valid assessment approaches was rare. CF providers were much more likely to use subjective approaches such as questioning patients and clinician

Table 3
Participant comments regarding challenges of providing adherence counseling.

Perceived ineffectiveness of adherence counseling	I spend considerable time trying to motivate and cajole nonadherent patients to get with the program. I have to say that I don't view this as on the whole terribly effective. I still do it, because it is my responsibility … I have had a few who, perhaps in a teachable moment or when they had reached the end of their rope, began to do their treatments and then felt better, but many times it seems as if I'm talking to a brick wall.
	We go over medications with every patient at every encounter. I personally spend an enormous amount of time dealing with compliance issues. I'm not convinced that this results in improved medication and treatment adherence.
	Addressing adherence to an individual's treatment regimen is crucial although I do not feel we are adequately trained.
Time burden of providing adherence counseling	… I also think that a big part of the burden in discussing lack of adherence falls on the physician so having a quick/effective way of doing this would help.
	I believe that adherence is important and improving adherence is an excellent way to improve [quality of life] and mortality. I would welcome suggestions that would help us improve adherence; however, I am very concerned about how I will find the time for the team members to do a more formal adherence intervention.
	I am interested in a program with the understanding that 15 additional minutes in an already very busy clinic is a large amount of time (especially with all of the other very complex patient related issues, clinical trials, and paperwork already required of the staff).

impression, than objective measures such as pharmacy refill records. Patient reports and healthcare provider estimates overestimate true adherence and providers are often no better than chance at identifying nonadherence [15,17]. Inaccurate assessments result in missed opportunities to provide patients and families with needed counseling and support. With the increasing availability of pharmacy records through e-prescribing and electronic monitors, such as the i-Neb [18,19], that provide data on patterns of medication adherence, it may soon become more feasible to regularly use objective measures [5]. These methods, however, provide copious amounts of data that must be reduced into metrics that are not only meaningful to clinicians and patients but may be easily integrated into clinic flow. For example, results embedded into electronic medical records will be more practical and sustainable than requiring clinicians to access outside portals. Future research is needed to validate these objective measures as well as identify and address the challenges to using them in clinical practice. Similarly, research is needed to identify the best way to display the data for providers and patients in a way that not only supports understanding but also has the greatest impact on behavior. Within and across countries there are differing philosophies about the ethics of accessing and using of pharmacy records and electronic monitoring with an overarching concern that the data will be used punitively to "catch" patients lying about their behavior and/or deny services. Care needs to be taken to minimize negative consequences, which may include educating training care teams, healthcare systems, payers, etc. about the risks and benefits of using this data.

It is concerning that almost 20% of centers assume that adherence is sufficient if lung function is stable or only discuss adherence if the patient is sick. Failing to address nonadherence before health problems arise leaves the patient to assume that they are "adherent enough" thereby reinforcing subpar behavioral habits that may be challenging to undo. Similarly, waiting until a person is having health problems may lead to a confrontational, rather than collaborative, interaction leaving the person with CF feeling judged, defensive, and less willing to engage in conversations about changing their behavior. Regardless of the patient's level of adherence, it is essential for CF care teams to approach the conversation in a collaborative and empathic manner to maintain a positive therapeutic relationship. For example, the use of patient-centered strategies, such as shared decision making and motivational interviewing, have been shown to be effective in improving adherence in other chronic illnesses and should be study specifically in CF [12,20].

Even when adherence was identified, only half the respondents felt that there was a consistent approach to intervening across care team members. Continuity and consistency are highly valued by parents of children with CF [21]. CF centers have become increasingly multidisciplinary which may lead to "too many cooks in the kitchen". Patients and families can easily become overwhelmed with the volume of recommendations and may receive mixed messages about the importance of adhering to various aspects of the regimen or how to overcome adherence barriers, leaving them on their own to decide how to best integrate their complex regimen into their daily lives.

Educational strategies were regularly provided to promote adherence; unfortunately, a substantial literature has demonstrated that improving knowledge is necessary but not sufficient [22]. Strategies such as providing written treatment plans and using a "Tell Me Back" approach have been shown to be effective for adherence promotion in other chronic illnesses [23,24] but were used by CF providers less often. Interestingly, adult centers were less likely to use these strategies compared to pediatric centers, perhaps reflecting an assumption that adults with CF already have the necessary knowledge. A promising finding is that centers regularly engaged in shared-decision making about the regimen, asked about adherence barriers and, if concerned about adherence, asked patients to return to clinic sooner. However, many providers did not proceed to the next level by providing specific advice or problem-solving on how to remember to do therapies, integrate the regimen into a busy life, or access social supports. These approaches have been shown to be important in promoting adherence in other chronic illnesses. Indeed, meta-analyses of adherence interventions suggest the most efficacious interventions are complex and multidimensional [25]. In a qualitative study about perceived value of CF care, the most common reason patients found CF visits unhelpful was they were too repetitive and patients did not learn anything new [26]. In the same study, helpfulness in providing knowledge and skills was associated with higher ratings of quality of care by parents and patients. Personalizing and tailoring adherence promotion

efforts is more challenging and time consuming, yet likely necessary to ensure that patients receive the appropriate advice and counseling to perceive clinic visits as worthwhile. These types of interventions should be develop and tested to evaluate their efficacy for people with CF.

As might be expected, inadequate time, clinic space, reimbursement, and access to adherence experts were common barriers to providing adherence counseling, as were concerns about whether the care team was effective in changing behavior. CF providers may be interested and ready to engage in training opportunities to improve their counseling skills, particularly if there is evidence that their efforts will improve adherence and health outcomes. How much time an intervention takes will clearly be a challenge given the drop in enthusiasm for a 15-min hypothetical intervention compared to one lasting 5 min. Therefore, from a sustainability perspective, interventions must be brief and easily integrated into the clinic setting. Unfortunately as noted above, the most efficacious interventions are complex and time consuming. Thus, in clinic settings as they are currently organized, there will be constant tension between efficacy and practicality. Alternative models for providing supplemental adherence support outside the traditional clinic visit therefore must be developed and evaluated with particular attention given to coordination and integration with the existing CF care delivery model.

The results of this survey must be interpreted within its limitations. This study included only one representative of the center's care team whose perceptions, beliefs, and behaviors may not fully reflect the center's typical approach to adherence promotion. Furthermore, actual frequency and quality of counseling delivered cannot be objectively determined. Despite a high response rate (62%), care centers who responded to the survey may not be representative of all care centers in the United States; hence, these findings may not be generalized to all centers, particularly for adult centers, which had a lower response rate, or centers outside the US. The lower response rate among adult providers relative to pediatric providers has been shown in previous research [4,28,29]. Centers choosing to participate likely reflect centers more aware and engaged in adherence practices with our results therefore reflecting a best-case scenario. Additionally, the association between care centers' adherence practices and patients' actual adherence or health outcomes was not measured; therefore, we cannot conclude that more frequent use of these behaviors results in better outcomes. Still, the adherence practices included in the survey do have a strong empirical basis as strategies to improve adherence [12,25] and adherence is associated with health outcomes in CF [2,3]. Finally, our questions focused exclusively on medication adherence and did not address airway clearance or nutritional adherence, which are also important components of the regimen. While it would have been informative to know if adherence practices differ by regimen tasks, it was decided that the resulting increased survey length would negatively impact the response rate. Future research should examine how centers address nonadherence to airway clearance, nutrition, and other aspects of the regimen.

Despite these limitations, these findings suggest many opportunities to improve the provision of evidence-based adherence promotion at CF care centers some of which involve minor changes to how a clinic session is organized and others that may necessitate larger system changes or further empirical evaluation. Given the CF community's commitment to quality improvement (QI) [27], it is suggested that centers use QI methodology to develop projects to ensure that adherence is assessed and addressed at each clinic visit, written treatment plans are provided, problem-solving is done with patients to overcome daily treatment barriers, etc. Few studies have evaluated the efficacy of adherence promotion interventions in CF populations and rarely are these interventions integrated with regular CF services. There is great opportunity to discover not only what strategies are most effective, but also what resources are needed to incorporate them into standard clinical care. Much as once-size-fits-all intervention will not improve patient adherence, a single, best approach does not exist to help care centers optimize their approach to intervening with their patients.

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